Patient Information Publications
Warren Grant Magnuson Clinical Center
National Institutes of Health

Bill of Rights for Clinical Center Patients

Whether you volunteer to participate in a research protocol as a healthy subject or as a patient, you are protected by the Clinical Center Bill of Rights for patients who are volunteer subjects. We, at the Clinical Center, believe that personal concern for every volunteer is indispensable to the quest for knowledge about disease. The most important person in medical research is the patient. The Clinical Center provides hospital facilities and professional care, but the patient is the essential element without which health and disease could not be observed or response to treatment measured.

Clinical Center patients' rights are safeguarded by procedures to ensure that all patients know their medical choices, and are aware of any risks from the procedures, and understand how research may affect them.

Members of the hospital staff have a responsibility to assure the following:

- the patient receives information necessary to make decisions about taking part in any research procedures
- care is given in a manner consistent with the patient's beliefs
- those rights basic to human dignity are observed.

This bill of rights for Clinical Center patients has been adapted from a similar document developed by the American Hospital Association for use by general hospitals.

1. The patient has the right to considerate and respectful care.
2. The patient has the right to know, by name, the physician responsible for coordinating his or her care at the Clinical Center.
3. The patient has the right to obtain from his or her physician complete current information about diagnosis, treatment, and prognosis in easily understandable terms. If it is medically inadvisable to give such information to the patients, it will be given to a legally authorized representative.
4. The patient has the right to receive from his or her physician information necessary to give informed consent prior to the start of any procedure or treatment. Except in emergencies this will include, but not necessarily be limited to, a description of the specific procedure or treatment, any risks involved, and the probable duration of any incapacitation.

   When there are alternatives to therapeutically designed research protocols, the patient has the right to know about them. The patient also has the right to know

the name of the person responsible for directing the procedures or treatment.

5. The patient has the right to refuse to participate in research, to refuse treatment to the extent permitted by law, and has the right to be informed of the medical consequences of these actions including possible dismissal from the study and discharge from the institution. If discharge would jeopardize the patient's health, he or she has the right to remain under Clinical Center care until discharge or transfer is medically advisable.

6. The patient has the right to be transferred to another facility when his or her participation in the Clinical Center study is terminated, providing the transfer is medically permissible, the patient has been informed of the needs for and alternatives to such a transfer, and the facility has agreed to accept the patient.

7. The patient has the right to privacy concerning the medical care program. Case discussion, consultation, examination, and treatment are confidential and will be conducted discreetly. The patient has the right to expect that all communications and records pertaining to care will be treated as confidential to the extent permitted by law.

8. The patient has the right to routine services whenever hospitalized at the Clinical Center in connection with the active protocol for which he or she is eligible; these services will generally include diagnostic procedures and medical treatment deemed necessary and advisable by the professional staff. Complicating chronic conditions will be noted, reported to the patient, and treated as necessary without the assumption of long-term responsibility for their management. The patient may be returned for long-term or definitive care of these conditions to the referring physician or to other appropriate medical resources.

9. The patient has the right to expect that medical information about him or her discovered at the Clinical Center, as well as an account of his or her medical program here, will be communicated to the referring physician.

10. The patient has the right, at any time during the medical program, to designate additional physicians or organizations to receive medical updates. The patient should inform the Outpatient Department staff of these additions.

11. The patient has the right to know in advance what appointment times and physicians are available and where to go for continuity of care provided by the Clinical Center when such care is required under the study for which the patient was admitted.

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This information is prepared specifically for patients participating in clinical research at the Warren Grant Magnuson Clinical Center at the National Institutes of Health and is not necessarily applicable to individuals who are patients elsewhere. If you have questions about the information presented here, talk to a member of your healthcare team.

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